THE SOCIAL AND PSYCHOLOGICAL EFFECTS OF SICKLE CELL DISEASE ON FAMILY FUNCTIONING

By

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This dissertation is dedicated to my husband, James E. Dekle, Sr., my children, Jamie Alesha and James Edgar, Jr., and my parents, Mr. and Mrs. Ed Foy Cone.

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Two and one-half million black Americans have sickle cell disease (SCD) of one form or another, almost one out of every 10 blacks in America. Doctors and health officials refer to it as "a world-wide problem," a "pressing health problem," and the most neglected health problem in the nation.

This study examined the impact of SCD on family functioning. Previous researchers have offered theoretical explanations as well as empirical evidence that chronic illnesses have a pervasive impact on the adjustment and quality of life for both the family and the individual.

The research suggests that there are specific areas that the illness may manifest its problematic properties. Chronic illness effects may present themselves as distorted family relationships, financial problems, marital problems, and depression in the primary caretaker.

This investigation examined the effects of SCD on (a) the family's economic resources; (b) the family's sense of social isolation from peer groups, relatives and friends; (c) marital satisfaction and relationship

problems; and finally (d) depression as experienced by the primary caretaker. The sample included 15 intact SCD families, 15 intact diabetic families used as an illness control group, and 15 intact nonillness families used as a normal control group. Information was also obtained and reported on an additional 10 families each of single parent sicklers and 10 nonillness single parents used as controls.

Several self-report inventories were completed by the subjects including the IPAT Depression Inventory, the Locke-Wallace Marital Satisfaction Inventory, the Parenting Stress Index, and the Impact of Illness on Family Scale. Data were analyzed by comparing the mean scores of the groups on the measures and determining whether significant differences existed between groups on the hypothesized variables.

Results were somewhat inconsistent. Sickler families appeared to be less impacted by the illness when compared to both the diabetic and nonillness controls. Both sicklers and diabetics reported that the illness impacted on their financial resources, but diabetics reported that the illness further impacted on their social relationships, their marital satisfaction, and relationship with their spouses. Also interesting was the finding that the nonillness controls were similar to diabetics in reporting greater family dysfunctioning than sickler families.

The author concluded that the inconsistent results could have been due to explanations related to coping strategies, denial of problems by families of sicklers, unreliability of instrumentation, and varying parental expectations. In addition, several methodological considerations were noted with emphasis on further study in the form of epidemiological and longitudinal research.

CHAPTER 1
INTRODUCTION

An Overview of Sickle Cell Disease

Two and one-half million black Americans have sickle cell disease (SCD) of one form or another, which roughly estimates to approximately one out of every ten blacks in America (Linde, 1972). These statistics may be a conservative estimate since it is only recently that interest in epidemiology, prevalence and prevention has increased. Doctors and health officials call it "a world wide problem," a "pressing public health problem," and the most neglected major health problem in the nation (Linde, 1972).

Sickle cell anemia (SCA) is an hereditary blood disorder. "Sickle Cell" refers to the shape of the red blood cells in the diseased individual. Normal red blood cells are saucer-shaped, or some people think they look like tiny donuts, kind of flat in the middle, with a raised rim around the outside. With sickle cells, the cells are not round and plump; instead, many of them are long and pointed or often curved, as in the shape of a sickle.

"Anemia" means that blood does not have enough red cells or enough hemoglobin to carry the oxygen to the body's tissues. In sickle cell, the anemia is caused because the abberant cells are more fragile than normal cells.

Much more common than SCA is the sickle cell trait. When a patient is heterozygous for the disease (or has one gene for it), this person carries the sickle cell trait. Sickle cell anemia occurs when a person carries two

genes for it (i.e. homozygous). Neel (1951) predicted that there was a 25 percent probability of the offspring of two trait parents having the disease. The person with the sickle cell trait can range from mild symptoms to having virtually no symptoms at all.

The incidence of sickle cell trait has also been found in non-Negroid ethnic groups. The trait has been found in countries bordering the Mediterranean as well as in parts of the Middle East, most notably among the ancient tribe of the Veddoids (Lehmann and Cutbush, 1952, Shukla and Solanki, 1958). Researchers have not agreed on the reason for the trait's presence in this isolated Indian group. There is no known evidence of contact between this group and Africans. Some researchers have theorized that there is a common ancestor for the Veddoids and the East African Negro who passed the gene for SCA to both. It has been hypothesized that the sickle cell trait had a protective quality in regions where malaria was common in that individuals who had the sickle cell gene did not appear to suffer from the more severe effects of malaria. It has been suggested that the sickle cell trait may have been passed from generation to generation because of its survival value.

An individual may have sickle cell trait and be unaware of it unless his blood has been specifically tested for it. Other persons with the sickle cell trait may have mild symptoms of one sort or another, but this happens only occasionally. Another condition that has been observed is one in which the individuals may not have any symptoms for years, but then suddenly develop symptoms under periods of stress (Cerami and Washington, 1974).

Sickle cell anemia is a chronic and debilitating disease that leads to a shortened life span. It is estimated that half of the children who

are afflicted die before the age of twenty (Cerami and Washington, 1974). The clinical manifestation of SCA affects most systems in the body. In discussing the clinical aspects of SCA, one important variable is the severity of the disease. Some individuals have a "stormy course" with many crises and complications that result in frequent hospitalizations and an early death. Others have a more benign form of the disease that allows them to lead more normal lives. However, there are symptoms present which are common to most persons who have SCD.

Symptomatology of Sickle Cell Disease

The most universal symptom of SCD is anemia. The degree of anemia varies from patient to patient and ranges from moderate to severe. The anemia of SCD is a result of the rapid destruction of sickled red blood cells. The life span of a red cell containing sickle hemoglobin (Hemoglobin S) is 30 days, less than a third that of the 120-day life span of normal red cells.

In individuals with SCD, the bone marrow which produces red cells expands drastically to keep up with this rapid destruction of the red cells. People with SCD produce seven to ten times the normal number of red blood cells. Consequently, every hollow bone in the body is utilized for red cells production. Because of the rapid destruction of these sickled red cells the muscle and other tissues of the individual receive a reduced or marginal supply of oxygen. If the individual exerts himself physically, he tires quickly because the muscles develop what is termed an "oxygen debt." At that point, the muscles will produce large amounts of lactic acid, a waste product that is thought to be responsible for pain and muscle fatigue.

In patients with SCD, the liver is unable to accommodate the increased production of bilirubin. Bilirubin is the result of a breakdown of hemoglobin into the heme and globin components. The bilirubin that results from the breakdown of the heme molecule is a red pigment. It is carried into the plasma (noncellular portion of the blood) where it is excreted into liver bile. The bile then goes into the gallbladder where it is concentrated. Because bilirubin is not soluble, it forms stones that can obstruct the bile ducts and lead to gallbladder disease. With the increased production of bilirubin, there is an increased level of bilirubin. This increase causes jaundice, a yellow staining of the skin and whites of the eyes.

After a period of time, as a result of the anemia and sickling process, the heart undergoes a number of changes. The most frequent modification is an enlargement of the heart. A large number of patients also develop functional heart murmurs. In addition, patients with SCD frequently develop cardiac arrythmias, or irregular patterns of heart beats.

Another common effect of the sickling process is chronic leg ulcers. Seen mainly in young adults, these ulcers occur in the ankle region and are slow to heal due to poor circulation.

The course of SCD also adversely affects the urogenital system. One of the most commonly observed aspects of this is a delay in sexual maturation of the external genitalia and secondary characteristics such as beard growth and breast development.

Although sickling can also affect the vascular supply to the brain, leading to serious neurological symptoms such as vasculitis and/or stroke, the incidence of such complications are infrequent. When

cerebrovascular occlusion does occur, patients exhibit the neurological manifestations similar to those observed with other vascular lesions. These manifestations may include drowsiness, paralysis, transistory or permanent blindness, aphasia, and generalized convulsions.

The skeletal system is frequently affected in the course of SCD. This is evidenced by (1) an increase in the size of the marrow cavities, (2) the death of bones because of the blockage of blood supply, and (3) an increased incidence of osteomyelitis, which is a bacterial infection of the bone. A common manifestation of the sickling is arthralgia or pain in the joint. This arthralgia is one of the major complaints of patients with this disease.

The disease manifestations described above create a chronic destruction of the patient's organs. In addition, there are periods of excruciating pain call "crisis". This pain is usually experienced in the abdomen, chest and joint, and it is believed to be caused by the entrapment of sickled cells and subsequent clogging of the capillaries of the tissues involved. The severity of the pain varies from mild, requiring only aspirin analgesia, to severe, which requires hospitalization. Most patients average two to three crises a year (Cerami and Washinton, 1974). A typical crisis leaves the patient in a state of weakness and exhaustion that requires two to three weeks for full recovery. The crises is an episode that is extremely taxing to the emotions and finances of patient and his family (Cerami and Washington, 1974).

Summary

The course of sickle cell disease affects a variety of physical and psychosocial processes in the identified patient. The primary

physical symptomatology is an anemia, which results from the sickling of red blood cells. In addition, the bone marrow, the liver, the skeletal system, the brain, and the muscles can be adversely affected by the course of SCD. Finally, although the sickle cell crisis is a physical manifestation of the disease, it is very psychologically taxing on the family as well as the individual.

CHAPTER 2
LITERATURE REVIEW

The Effects of Chronic Illness on Family Functioning

Theoretical Studies

Theoretically, research literature has suggested that chronic illnesses, such as sickle cell anemia, childhood diabetes, chronic renal failure, cystic fibrosis, and their clinical manifestations have a pervasive impact on the adjustment and quality of life for both the family and the individual (Burton, 1975). Bruner (1966) observed that in families of chronically ill children each family member has to adjust its coping style in a juxtapositional fashion to the chronic disease. He surmised that when the individual and the family can cope and adjust to a chronic illness this brings about relief, reward, quiescence, and equilibrium within the family system.

McCollum (1981), Debuskey (1970), and Whitten and Fischoff (1974) have related family adjustment to the adjustment of the affected member. In their observations, they have found that adjustment of the family has been correlated with successful coping of the chronically ill individual.

Several categories of variables have been found to affect families of the chronically ill. Lipowski (1970) identified three variables which he labeled intrapersonal, environmental, and illness-related. Intrapersonal family factors include personality of the family unit, specific care skills, values, beliefs, emotional state and cognitive

capacity of the family. Environmental factors include presence of a support network, access to health services and financial resources. Illness-related factors include type of illness, degree of impairment, meaning of the illness to the family, and stage of progression of the illness. Charmaz (1973) outlined a three-stage progression of chronic disease and its effect on family functioning. Stage One is "interrupted time" when daily activities need to be adjusted to obtain a diagnosis. Stage Two is the "time intrusion" phase when daily activities need to be adjusted to control the effect of the disease. The illness consumes time and energy. Stage Three is labeled "time encapsulation" during which the family is consumed by the illness and the family is engulfed with care management throughout the day. It is within these three stages that maladaptive responses to the chronic illness can develop.

Healthy family functioning is expressed by some as a "complimentary of family relationships" (Ackerman, 1966, pg. 72), which is defined as quality of circular support, interdependence, and intimacy molded by the need to understand and care for each other. Hallmarks of family healthiness include affection, caring, and loyalty. The starting point of family dysfunctioning is an inability to adapt to differences and change on the part of family members. There is an unwillingness or an inability to adapt to new roles due to circumstances or situations that touch the family.

Bowen (1971) characterized healthy family functioning as freeing one's emotions and expressiveness. Pathologic manifestations of unhealthy family functioning masked itself as marital discordance, triangulation and scapegoating. Triangulation and scapegoating refer

to a conflictual situation between two persons who involve a third person. This conflictual pattern often stabilizes and becomes chronic.

Empirical Studies

The impact of chronic illness on family functioning has received some empirical attention in the literature, although much of our knowledge is based on theoretical suppositions and clinical intuition. Straus and Glaser (1975) observed families over time and found that everyday mood and interpersonal relations are affected by chronic illness. Such effects are manifested in reduced numbers of behaviors such as visiting friends and engaging in other leisure time activities. Financial conflicts and tensions are also engendered by increased expenses stemming from medical treatment.

McCollum (1981) observed that when a child develops a threatening illness, grief is inevitable for those who care about him. Families grieve not only for the feared loss of the child, but also for the loss of certain hopes and dreams for him. McCollum also observed that parents of sick children seem destined to experience guilt to some degree. The guilt may take the form of feeling responsible for the illness by feeling that one gave less than ideal care, by feeling there was neglect or delay in seeking medical advice, or guilt about carrying a particular genetic trait.

She observed that families who experience grief and anxiety often describe an increase of irritable feelings toward one another. Parents may feel alienated from one another. One of the spouses may become distant and aloof which can lead to marital disharmony and dissatisfaction. Usually there is another child in the family who becomes

the target of irritability, i.e., scapegoating, which often leads to fleeting moments of resentment of the healthy children (McCollum, 1981).

The closest, most devoted couples may sense the strain, yet others may feel like hostile strangers. The marriage becomes vulnerable, with the threat to a child, rather than drawing them together, alienating them from each other (McCollum, 1981).

Satterwhite (1978) surveyed families of children with chronic illness and reported that parents experience financial problems, worries about the future of the child, and feelings of guilt and isolation. Burton (1975) surveyed families and found increased marital tensions and parent-child conflicts.

Tew and Laurence (1972) found that mothers of children with spina bifida were found to have higher "stress scores" than mothers of children with other problems. Gayton, Friedman, Tavormina and Tucker (1982) found that mothers of children with cystic fibrosis had higher depression scores on the Minnesota Multiphasic Personality Inventory, compared with "control subjects". These studies have been criticized from the standpoint of not utilizing adequate or appropriate controls, as well as having sampling problems. More importantly, the effects of the child's illness from other potential causes of psychological distress were not adequately separated (Breslau, Staruch, Mortimer, 1982). This criticism has become one of the major criticisms in the area of correlating chronic illness in children to psychological distress in families.

Turk (1964) examined the impact of cystic fibrosis on the family. She found that parents felt deprived of time and energy to engage in leisure time activities for the family; time to be alone with spouse

time and energy to engage in adult activities and/or time for one-self. Significant problems in communication between members of these families were also observed. For example, parents were able to discuss treatment of the sick child but were unable to communicate on other subjects related to family functioning. This study supports the contention that chronic illness affects family functioning. However, the author failed to utilize a control group to assess the degree of differences between chronic illness and other types of families such as psychological/chronic psychiatric families and/or nonillness families to identify adaptive versus maladaptive functioning.

Maurin and Schenkel (1976) studied 20 family units of patients with end stage renal failure. They found that minimal overt communication occurred between all family members. In addition, there appeared to be a withdrawal from social life into a very family-centered existence.

McMichael (1971) surveyed parents' emotional difficulties with children who had varying severe physical handicaps. Results showed that 28 out 50 patients, or 56 percent, experienced moderately severe degrees of anxiety and failure to adjust. Factors predisposing parents to anxiety and emotional difficulties were severity of the physical handicap, prognosis of the illness, fears concerning the child's future, family life, fears about ultimate care of the child and the possible need for institutional care of the child. The anxieties related to the parents themselves were fear of future pregnancies, marital disharmonies and separation, and parental ill health.

Breslau, Staruch, and Mortimer (1982) examined the psychological distress of mothers of disabled children. Scores on a depression-anxiety

scale was used to describe "the unpleasant feelings of which people are aware" and is specific to a woman's experience as a mother. The sample consisted of 369 mothers of children with cystic fibrosis, cerebral palsy and multiple handicaps were compared to those of 456 mothers from a randomly selected sample of families (control subjects). Mothers of disabled children scored significantly higher than control subjects on both indices of psychological distress. This finding persisted even when control for mother's education, family income, and racial composition were utilized. Type of disability, i.e., diagnostic classification of the disabled child was unrelated to the mother's level of psychological distress. In contrast, the disabled child's dependency on others in daily activities had a significant effect on both measures of psychological distress. The more dependent the child, the greater the mother's distress. This study provided much insight into the issue of chronic illness on family functioning. However, it is more than likely that dependency is very much related to type of illness. The physical characteristics of the illness probably affects to a large extent how independent or dependent a child will be from both a mental and physical standpoint. Diagnostic classification and dependency could more be expected to be correlated than these authors have observed.

Summary of Review of Literature

In general, when several types of classification of chronic illness have been examined, research findings suggest that a chronic illness affects the unique functioning of the family in which it occurs. Distorted family relationships, financial burdens, marital discordance, anxiety, guilt, depression, and withdrawal from friends and other support systems have all been reported. Furthermore, these effects have been

shown to occur even when possible confounding variables such as socio-economic status, education of mother, and racial composition of parents are controlled for. Families are affected by the pain component of the illness, the unpredictability of the illness, the dependency of the child, issues related to death and dying, and the severity of the illness. One can speculate that type of illness may be related to type of effect; however, present research clearly supports the suggestion that a chronic illness effects areas of family functioning and survival.

Empirical analysis of the variables that have been theorized and hypothesized as being problematic within chronically ill families have been limited. Previous research can be criticized for a number of weaknesses, including a lack of adequate control groups, both illness and normal controls, sampling problems, and the tendency to generate from too-small sample sizes. In addition, the specific variables that have been theorized as being important have not always been operationalized such that they can be consistently measured across studies. This limitaton leads to possible reliability and validity problems. In the following section, and examination of the literature on the impact of SCD on family functioning is presented which reveals even more apparently the weaknesses of research in this area.

Review Studies of SCD on Family Functioning

Psychosocial effects of SCD on family functioning has received remarkedly little investigation in the literature. The information that is available has its basis primarily in theoretical formulations and clinical observations and impressions (Graham et al., 1982; Vassassuer, 1977; Leavell and Ford, 1982; Whitten and Fishchoff, 1974). A review is presented below with specific emphasis on SCD and its impact.

Whitten and Fishchoff (1974) utilized clinical observations to propose that parents of SCD children may experience several areas of concern. These include fears about the child with respect to his ability to achieve social and economic success, resentment of having very dependent child whose care may frequently inconvenience them, guilt over being responsible for the child's illness, and anxiety about potential early death. There may be anger over economic problems related to frequent hospitilizations, as well as feelings of embarrassment, shame, and displeasure of the child's size.

Vassasseur (1977) noted that parents of SCD children are prone to anxiety and fears which decrease their sense of power in confronting the illness. Graham et al. (1982) have noted that parents of SCD children have major problems with inferiority. They hypothesized that this may be the case because SCD deprives parents of the opportunity to experience a successful, early stage of development with their baby, and by so doing, to improve their own sense of self-worth. However, the authors' formulation and/or impressions of inferiority in parents of SCD may have little to do with the disease process, but with what may often be a general feeling of inferiority that is found in some members of the black culture.

Feelings of blame may be present which often lead to severe marital discord and inappropriate placement of blame (Williams, Earles and Pack, 1983). Parents may feel that they are to blame for the child's illness and try to overindulge their child in attempts to correct the anemia, or they will try to cure their child with other types of remedies.

Summary of Review

The limited research available suggests that the effects of SCD on family functioning seem to to become manifested as feelings of anger,

resentment, embarrassment, inferiority, blame and guilt experienced by the parents. However, most of this information is based upon inferences about clinical observations of these families. Unfortunately, the lack of control groups may lead to inferences which reflect stereotypes about the black family rather than specific effects of the illness on family functioning. There is a limited amount of knowledge related the normal functioning of the black family. Until more is known about normal black functioning, one cannot adequately assess what is adaptive or maladaptive within this culture. Furthermore, lack of this basic information limits the degree to which one can assess the impact of chronically ill children on the functioning of the black family.

Rationale

Despite the limitations of available research noted earlier, one cannot dismiss the fact that have been several factors found to affect functioning in families of chronically ill children. This study focuses on some of these variables with specific interest in how they are manifested in black families. Previous research has suggested that feelings of guilt, anger, fear, and inferiority are problems with SCD families. However, research in families with other types of chronic illness indicates that the effects appear to be more confined to the areas of financial strain, social isolation from peers and friends, marital discordance, and mild to moderate depression in the primary caretaker. Is there such a discrepancy in the way SCD affects the family versus other chronic illnesses? Indeed, if this is the case, treatment approaches would need to be modified in such a way as to meet the individualized

needs of the family and the individual. Or should one assume that just as these variables are operable in the general population of chronic illnesses, they are also operable in SCD families. Intuitively, the answer seems to be an unequivocal yes. However, this question has not been systematically examined in SCD families.

In the present study, an attempt was made to examine the effects of SCD on family functioning. The design utilized several assessment techniques as well as employed both a diabetic and a normal control group of families. The families were similarly matched to SCD families on several demographic variables such as: family size, socioeconomic status, and age of identified child. Using this methodology, major similarities and disparities between "illness families" and normal families were more readily assessed in terms of the impact of the illness. In addition, results from this study will provide information specifically related to black families in identifying and learning how they manage problems associated with having a chronically ill child.

To summarize, this investigation examined more closely the effects of sickle cell disease on (a) the family's economic resources, (b) the family's sense of social isolation from peer groups and friends, (c) marital satisfaction and related problems, and finally, (d) depression as experienced by the primary caretaker.

The following hypotheses were formulated and investigated by statistical analysis of data collected for this study.

1. There will be no significant differences between families with chronic illness due to sickle cell disease and families with chronic illness due to diabetes in terms of the effects of the illness on the families' economic resources as measured by the Impact of Illness on Family Scale (IFS).

2. There will be no significant differences between families of sicklers and families of diabetics on the effects of the illness on the quality of social relationships as measured by the IFS.

3. There will be no significant differences between the families of sicklers and families of diabetics on the total impact of the illness on the family as measured by the IFS.

4. There will be no significant differences between families of sicklers, diabetics, and nonillness controls on depression of primary caretaker as measured by the Parenting Stress Index (PSI).

5. There will be no significant differences between the illness families and the nonillness control families on the effects of the illness on social isolation and quality of social relationships as measured by the PSI.

6. There will be no significant differences between illness families and nonillness families on the effects of the illness on the quality of the marital relationship and the relationship with spouse as measured by the PSI.

7. There will be no significant differences between illness families and nonillness families on marital satisfaction as measured by the Locke-Wallace Marital Inventory.

8. There will be no significant differences between the illness families and the nonillness families on the effects of the illness on depression as experienced by the primary caretaker as measured by the IPAT Depression Inventory.

CHAPTER 3
METHODS

Subjects

The primary subjects of the study consisted of three groups of intact families: 15 families of children with sickle cell disease, 15 families of children with juvenile diabetes (JD) and a nonillness control group of 15 families. The SCD families were recruited from outpatient sickle cell clinics across Georgia and northern Florida. The juvenile diabetic families were recruited from outpatient clinics across Georgia as well. Normal families were recruited through local churches, auxiliaries, and the school system. Subjects were similarly matched on variables of socioeconomic levels, family size, age range of identified child, and education of mother and father. It should be noted that all subjects in both the sickler group and the nonillness control group were black, whereas 80% of the diabetic families were white. There was no attempt to control for racial differences since it was felt that the occurrence of the diseases as found in different racial groups is due to natural circumstances of which cannot be controlled.

Though they were not the primary focus of the study, additional subjects of the study consisted of two groups of single parent families, namely sickle cell disease and a nonillness control group. There were 10 families in each of these groups. While attempting to recruit 25 SCD intact families, it was observed that single parent families made up a considerable percentage of SCD families utilizing

outpatient services. It was decided that even though data from this sample would be the primary focus, it would provide some interesting insights into the functioning of single parent families and possibly allow for some comparisons to be made to intact families of chronically ill children. All subjects in these two groups were black.

Materials

Data were collected for each sickler, diabetic, and nonillness control family on: (1) selected stress related scales as measured by the Parenting Stress Index (PSI); (2) depression as experienced by the primary caretaker as measured by the IPAT Depression Inventory; and (3) marital satisfaction and relationship with spouse as measured by the Locke-Wallace Marital Inventory. Additional data were collected for each sickler and diabetic family on (1) the Financial Impact scale and the Disruption of Social Relationship Scale as measured by the Impact of Illness on Family Scale (IFS). Data were collected on each of the single parent sicklers and nonillness control families on selected variables on the PSI and (2) depression as measured by the IPAT. Following is a description as well as psychometric data on each of the instruments used in the study.

The Impact of Illness on Family Scale (Stein and Jessop, 1985). The objective of this scale is to measure the effect of the child's condition in producing change in the family. Impact is conceptualized as the effects of the child's illness on the family system. Four dimensions were theorized as revelant: economic (changes in the economic status of the family), social (the quality and quantity of others outside of the family), familial (quality of interaction within the family unit), and strain (subjective burden experienced by the primary caretaker).

An item pool for each hypothesized dimension was created using qualitative data from patient interviews, reviews of the literature and clinical experience of providers who treat chronically ill children. Psychometric data were used to further refine the scale and factor analysis of the first 100 cases revealed four dimensions of impact on the measure: financial, social/familial, personal strain, and mastery. Three of the four hypothesized dimensions were empirically demonstrated by the factor analysis, two theorized dimensions combined in one (familial/social), and a new one was generated (coping or mastery). The twenty-four item scale elicited variability in response and was internally consistent.

The construct validity of the Impact on Family Measure has been extended with analyses of the data on 209 cases. Dataset suggest that the Impact scale is in fact tapping the construct it was designed to measure. Higher Total Impact on Family Scale is associated with low education, low family income, the presence of welfare, a mother's perception that her child is difficult to care for, poor functioning on the part of the child, increased number of hospitalizations and other forms of utilization, days absent from school, poor psychological adjustment on the part of the child, and increased psychiatric symptoms on the part of the mother.

The Locke-Wallace Marital Inventory Locke and Wallace, 1959). The Locke-Wallace Marital Inventory is a 15-item questionnaire used to measure marital adjustment. The reliability of the adjustment tested, computed by the split-half technique and corrected by the Spearman-Brown formula is .90 (Locke and Wallace, 1959). In examining the

validity, it was found that the test adequately differentiated between persons who were well-adjusted and those who were maladjusted in marriage. The sample was predominantly young native white, educated, white collar and professional, urban group. They were predominantly childless or had only one child. Mean length of marriage was 5.6 years for husbands and 5.3 years for wives. The mean adjustment score for the well-adjusted group was 135.9, whereas the mean score for the maladjusted was 71.7. Only 17 percent of the maladjusted group achieved adjustment scores of one hundred or higher, whereas 96 percent of the well-adjusted group achieved scores of one hundred or more.

The IPAT Depression Scale (Krug and Laughlin, 1976). The IPAT Depression Scale is a measure used to study the physical and emotional symptoms of depression. The IPAT is a 40-item scale. Norms are provided for men and women together in an equally weighted combination as well as for women separately and men separately.

Alpha coefficients for the IPAT scale range from .85 to .93. Parallel split-half reliabilities range from .89 to .94 (Krug and Laughlin, 1976). Validity measures showed that a correlation of .88 was obtained between the 36 item scale and pure depression factor in a sample of 1904 normals and clinical cases. The IPAT scale also discriminated a group of normals for a diagnosed group of depressives with the overall mean difference yielding a t of 13.52 (df=697), which was highly significant.

The IPAT correlates .82 with the Clinical Analysis Questionnaire. The IPAT also correlates significantly with the depression scale on the Minnesota Multiphasic Personality Inventory, $r=.31$ $p < .05$ level of significance.

The norms for the Depression scale were based on slightly more than 2,000 cases which were randomly sampled from a larger group of nearly 3,000 cases, sampled across 10 occupational classes. The largest single group represented in the "minority" description was black, but sampling included American Indians, Orientals, and Spanish Americans. However, 84.37 percent of the normative group were white and 15.7 percent were non-white.

The Parenting Stress Index (PSI) (Albidin, 1983). The PSI identifies three major source domains of stressors: (1) child characteristics, (2) parent characteristics, and (3) situation/demographic characteristics. With regard to the kinds of stressors identified, they ranged from objective life events such as death of a family member to the mother's judgment of the child's activity level, to the parent subjective feelings of being trapped by their parenting responsibilities.

From initial development, which consisted of 150 items, several revisions have occurred. Presently, Form six of the PSI is considered the current form which consists of 101 items with an optional Life Stress scale. Below is a brief description of each scale on the PSI.

Scale 1. Adaptability/Plasticity High Score = 31

Description: High scores on this scale are associated with characteristics which make the mothering task more difficult by virtue of the child's inability to adjust to changes in his or her physical or social environment.

Scale 2. Adaptabiltiy of Child to Parent High Score = 17

Description: High scores are produced in this area when the child possesses physical, intellectual and emotional characteristics which do not match the parent's hope for the child.

Scale 3. Child Demandingness High Score = 24

Description: High scores in this area are produced when parent experiences the child as placing demands upon him/her.

Scale 4. Child Distractability/Hyperactivity High Score = 31

Description: High scores on this subscale appear to be associated with children who display many of the behaviors found in the Attention Deficit Disorder with Hyperactivity as described by the DSM III.

Scale 5. Child Reinforces Parent High Score = 12

Description: The parent who earns high scores does not experience her child as a source of positive reinforcement. The interactions between parent and child fail to produce good feelings by the parent about the child.

Scale 6. Parent Attachment High Score = 16

Description: High scores suggest that parent does not feel a sense of emotional closeness to the child. In addition, high scores suggest the parent's real or perceived inability to accurately read and understand the child's feelings and/or needs.

Scale 7. Restrictions Imposed by Parental Role High Score = 26

Description: High scores suggest that parents involved experience the parental role as restricting their freedom and frustrating in their attempts to maintain their own identity.

Scale 8: Parent's Sense of Competence High Score = 37

Description: High scores suggest parents who are lacking in knowledge of child development or who possesses limited range of child management skills. Also high scores will be found among parents who do not find the role of parent as reinforcing as they had expected.

Scale 9. Social Isolation High Score = 18

Description: High scores are suggestive of parents who are socially isolated from other peers, relatives, and other emotional support systems. In many instances their relationships with their spouses are distant and lacking in support for their efforts as parents.

Scale 10: Relationship with Spouse High Score = 23

Description: Parents who earn high scores are those who are lacking the emotional and active support of the other parent in the area of child management.

Scale 11. Parental Health High Score = 16

Description: High scores are suggestive of deterioration in parental health which may either be the result of stress or an additional stressor in the parent-child system.

Scale 12. Child Characteristics Domain High Score = 122

Description: High scores are associated with children who display qualities which make it difficult for parents to fulfill their parenting roles. When this scale is elevated in relation to the other domains, the suggestion exists that certain characteristics of the child are major factors in contributing to the overall stress in the parent-child system.

Scale 13. Parent Characteristic Domain High Score = 153

Description: High scores suggest that the sources of stress and potential dysfunction of the parent-child system may be related to dimensions of the parent's functioning.

Scale 14. Total Score High Score = 260+

Description: High scores suggest a parent child system which is under stress and at risk for the development of dysfunctional parenting behaviors or behavior problems in the child involved.

Normal Range for Total Score 180-250

Description: Normal range of the total score is approximately the 15th to the 80th percentile. It is possible for parents to earn a total score within this span and yet earn a domain score which falls in the critical range either above or below normal range.

Extremely Low Total Score 175

Description: Type I false negative: Some parents who earned extremely low scores tend to be very defensive, tearful, and mildly paranoid. Often these parents react as to say, "If I admit I have problems, I will fall apart and be overwhelmed." Type II false negative: These are individuals with little investment in the role of parenting. Typically they are minimally involved with their children.

Validity studies of the instrument have been performed by several researchers since its development. Concurrent validty was demonstrated

in studies by Lafiosca (1981), Awalt (1981), and Casey (1983). Discriminant validity was demonstrated in studies performed by Zimmerman (1979), Greenberg (1983), and Saviano (1981).

Reliability coefficients were determined for each subscale, each domain, and each total score. The reliability of coefficients were computed on responses of the sample of 534. Coefficients ranged in magnitude from .62 to .70 for the subscales of the child domain and from .55 to .80 for the subscales of the parent domain. The reliability coefficient for total stress scores was .95.

The stability of the PSI scales was supported by test-retest reliability obtained from a study by Burke (1978). The PSI was administered to 15 mothers visiting a well-care pediatric clinic. The PSI was again administered three weeks later. A Spearman rank-order coefficient of .817 and .706 were obtained for the child domain and parent domain respectively ($p<.01$), and a strong relationship for scores across a three-week interval.

The normative group consisted of 534 parents in a large part from those parents visiting small pediatric clinics in Virginia. In the normative group demographically, approximately 92 percent were white and 6 percent were black. A wide range of incomes were represented: approximately one-fourth of the families had total incomes less than $10,000 and one-fourth had incomes greater than $20,000. Educational levels were relatively high, with approximately one-third of mothers and fathers having graduated from college or professional school.

Procedures

All information was provided by the mothers of the chronically ill child. Participants were told the following:

> My name is Cynthia Cone-Dekle, a student at the University of Florida. I want to learn more about SCD (JD) and how it has affected you and your family. I realize that this is a very sensitive and personal issue, but what you share with me today will enable me and others in this profession to help families that may be experiencing similar problems as your family. We do not know a lot about the effects of a chronic illness on the family, so I decided that the best place to learn about it was to talk with families directly. You will be filling out several questionnaires that will probably take about one hour and thirty minutes of your time. Do you have any questions? I will wait here until you have finished.

Normal participants were given the following instructions:

> My name is Cynthia Cone-Dekle, a student at the University of Florida. I have been talking with families of children with sickle cell disease and juvenile diabetes. They have shared with me some of the problems they experienced as a result of having a sick child. Now I am talking with normal families like yours, asking them similar questions and giving them questionnaires. I would like to compare the responses of normal families with those of chronic illness families to see how the problems within these two type of families differ. You will be filling out several questionnaires that will take approximately one hour and thirty minutes of your time. Do you have any questions? I will wait here until you have finished.

After the basic instructions were given, participants filled out the questionnaires. To a brief extent, when parents completed the questionnaires they were allowed to discuss any issues or concerns that may have evolved as a result of the testing.

Due to institutional regulations of two clinics, a signed consent form was required and completed by the participants. A copy of the consent form is found in Appendix A.

Statistical Procedures

All information was hand scored by the investigator. Statistical procedures of data were performed using the program entitled Statistical Package for Social Sciences-X (SPSS-X) with the cooperation of Georgia Southern College, Statesboro, Georgia. Michael Tood, statistician served as chief consultant. By utilizing single classification analysis of variance, the investigator made the following comparisons:

1. of the mean scores on each of the demographic variables for families of sicklers, diabetics, and nonillness controls;
2. of the mean scores on each of the demographic variables of single parent sicklers and nonillness controls;
3. of the mean scores on the marital satisfaction score of families of sicklers, diabetics, and nonillness controls;
4. of the mean scores on depression of families of sicklers, diabetics, and nonillness controls; and
5. of the mean scores on depression of single parent sicklers and nonillness controls.

By utilizing multivariate analysis of variance, the investigator made the following comparisons:

1. of the mean scores on the social isolation scale, the relationship with spouse scale and the depression scale of the PSI of families of sicklers, diabetics, and nonillness controls;
2. of the mean scores on the social isolation scale, relationship with spouse/child's natural father, and depression scale of the PSI of single parent sicklers and nonillness controls: and

3. of the mean scores on the financial impact scale, the disruption of social relationship scale and the total impact scale on the IFS of families of sicklers and diabetics.

In order to determine whether significant differences occurred, F ratios were required to be significant at the .05 level of confidence. Where significant F ratios were found, the t-test of independent means was used to determine where the significance existed internally. The .05 level of confidence was used to determine the existence of significant differences.

CHAPTER 4
RESULTS AND DISCUSSION OF FINDINGS

This chapter is divided into seven main sections. The first section presents the results of the differences in demographic variables for intact families of sicklers, diabetics, and nonillness controls, as well as for single parent sicklers and single parent nonillness controls. The second section includes the results of differences of (a) IFS scales Financial Impact and Disruption of Social Relationships for families of sicklers and diabetics and (b) the results of a comparison of the IFS Total Impact mean scores for families of sicklers and diabetics, and the standardization group. The third section of this chapter includes results of differences in PSI variables Social Isolation, Relationship with Spouse, and Depression for families of sicklers, diabetics, and nonillness controls. Section four includes the results of differences in marital satisfaction as measured by the Locke-Wallace Marital Inventory for families of sicklers, diabetics, and nonillness controls. The fifth section includes the results of differences on the IPAT Depression Inventory for families of sicklers, diabetics, and nonillness controls. The sixth section includes the results of differences in the analysis of selected variables for single parent sicklers and single parent nonillness controls. The final section includes the results of differences on data obtained from additional PSI scales for intact families of sicklers, diabetics, nonillness controls, and single parent sicklers and single parent nonillness controls. It should be noted that data

from section six and seven were not considered as part of the primary study. They were included because while collecting the data of interest these insightful findings were also obtained. The investigator decided that these results should be reported and discussed to some extent.

Section One

Analysis of the Differences of Demographic Variables Between Groups

Analysis of demographic data was performed to determine (1) whether the groups were similarly matched on the variables the investigator was attempting to control for and (2) to determine whether the single families and intact families were similar enough such they they could be combined to increase the sample size. Table 4-1 summarizes the mean raw scores and standard deviations for demographic-subject characteristics for both the intact families and the single parent ones.

Table 4-1
Mean Raw Scores for Demographics-Subject Characteristics

Group	N	Age of Child	*Income *Level	Education **Mother	Education **Father	Family Size
Sicklers	15	6.7	17.4	.667	.933	4.7
S.D.		2.49	9.11	.488	.258	1.52
Diabetics	15	6.4	27.3	.867	.800	4.7
S.D.		2.19	17.8	.352	.414	1.11
Normals	15	6.7	18.9	1.00	.800	4.8
S.D.		2.25	10.4	0.0	.414	1.14
Sicklers	10	6.4	7.9	.800	.900	3.6
S.D.		2.67	1.28	.422	.316	1.71
Normals	10	6.1	10.7	1.00	1.00	3.2
S.D.		2.76	5.43	0.0	0.0	.91

*measured by the thousandth
**raw scores tabulated as: 0=non-high school graduate
1=high school graduate

Using a single classification ANOVA, an analysis of significant differences between intact families was performed. Analysis revealed significant differences $F(2,44)=3.500$ $P<.03$ between sicklers, diabetics, and controls on the variable of education of mother. Table 4-2 summarizes these results.

Table 4-2
Summary Table of Analysis of Variance on Demographics-Subject Characteristics
Families of Sicklers, Diabetics and Controls

Variable	F-Value	Significance of F
age of child	.081	.923
income	2.411	.102
education of mother	3.500	.039
education of father	.651	.527
family size	.431	.653

Further analysis was performed to determine where the significance existed internally. A t-test of independent means revealed that significant effects of education were seen between diabetic mothers and sickler mothers, t (28) = 2.125 $p<.05$, and between the nonillness control mothers and sickler mothers, t (28) = 3.333 $p<.05$. There were no significant effects of education between diabetic mothers and nonillness control mothers. The results indicated that diabetic and nonillness control mothers were more likely to have at least a high school education when compared to the sickler mothers.

Using a single classification ANOVA, an analysis of significant differences between single parent families was performed. Table 4-3 displays these results.

Table 4-3
Analysis of Variance of Demographics-Subject Charcteristics
Single Parent Sicklers and Single Parent Controls

Variable	Value of F	Significance of F
age of child	.106	.748
income	.200	.660
education of mother	2.250	.151
education of father	1.000	.331
family size	1.038	.322

No differences in demographic variables were observed in this comparison.

In order to determine whether the intact sickler family group and the single parent sickler family group could be combined in order to increase the sample size, an analysis of significant differences between all groups combined was performed. Table 4-4 summarizes these results.

Table 4-4
Analysis of Variance of Demographic-Subject Characteristics
Intact Families and Single Parents Combined

Variable	N	Value of F	Significance of F
age of child	65	.114	.976
income	65	5.044	.001
education of mother	65	2.446	.056
education of father	65	.864	.491
family size	65	4.584	.003

The analysis revealed significant effects were observed on the variables of income, $F(4,64) = 5.044$ $p < .001$, Education of mother $F(4,64) = 2.446$ $p < .05$, and Family Size, $F(4,64) = 4.584$ $p < .003$.

From the preceding results, the experimenter concluded that the results for the groups would be best analyzed and reported separately due to the dissimilarity of the groups on three of the demographic variables.

Section Two

Analysis of Impact of Illness on Family Scale (IFS)

The Impact of Family scale was used to examine the effects of the illness on the family's economic resources, social relationships, and to some degree assess the overall level of stress and dysfunctioning within the family. The IFS was only appropriate with families of sicklers and diabetics or only the illness groups. Table 4-5 summarizes the mean scores on the IFS for the diabetic and sickler families.

Table 4-5
Mean Scores on Impact of Illness on Family Scale

Group	Total Impact	Financial Impact	General Impact	Disruption Social	Coping
sicklers	44.8	6.73	23.6	18.3	7.93
S.D.	4.97	.884	2.92	2.66	1.71
diabetics	45.3	7.07	24.7	21.6	8.53
S.D.	4.11	.884	2.06	3.66	1.24
Normative sample*	48.03	7.70	25.45	20.8	7.90
S.D.	8.20	1.77	4.85	4.13	1.51

*this group included for further comparisons

The first variable under scrutinization was the effect of the illness families' economic resources, thus the Financial Impact scale was used. The following hypothesis was formulated: There will be no significant

differences between sicklers and diabetics on family's economic resources as measured by the IFS. Table 4-6 summarizes the statistical relationship between the groups.

Table 4-6
A Summary of MANOVA for Intact Sickler and Diabetic Families for IFS Variables

Scale	N	F-Value	Significance of F
Total score	30	.078	.781
Financial Impact	30	1.067	.310
General Impact	30	1.831	.187
Disruptions/Social Relationships	30	8.143	.008
Coping	30	1.206	.281

A multivariate analysis of variance revealed no significant differences between the groups in terms of impact of illness on financial resources. Since the analysis of variance on the factor of financial impact failed to exceed the critical value required for significance, the null hypothesis was accepted. Further comparison of mean scores on financial impact for families of sicklers and diabetics was achieved by comparing them to the standardization group. Similar mean scores were observed as seen in Table 4-6. Interpretably, the range of scores of the present sample groups were similar to the normative group range. Scores of this magnitude suggest that the present sample was similar to the normative sample in reporting that the illness contributed to adverse changes in the economic status of the family.

IFS Disruption of Social Relationship scale was the second variable to be analyzed. The following hypothesis was formulated: There will be

no significant differences between sicklers and diabetics on quality of social relationships as measured by the IFS. The MANOVA revealed significant differences $F(2,28) = 8.143$ $p < .008$ between the groups in terms of impact of illness on disruption of social patterns. Again, these results are reflected in Table 4-6. The diabetic families reported significantly more than the sicklers that the illness affected the quality and quantity of interaction with others outside of the family in that there were fewer in number and the relationships were less intense. Since the analysis of variance on the factor of Disruption of Social Relationships exceeded the critical value required for significance, the null hypothesis was rejected. Again, a comparison was made between families of sicklers, diabetics, and the normative group on the social isolation scale. The comparison revealed mean scores of 18.3, 21.6, and 20.8 respectively. A similar pattern emerged between all three groups, with all three reporting the illness impacted on their social relationships in varying degrees.

The final analysis on the IFS was an examination of the Total Impact score. The following hypothesis was formulated: There will be no significant differences between groups on the Total Impact scale. Again, Table 4-6 displays these results. The MANOVA revealed no significant differences between the groups in terms of this scale. Since the analysis of variance on this factor failed to achieve significance, the null hypothesis was accepted. A comparison of mean scores of sicklers, diabetics and the normative group disclosed mean scores of 44.8, 45.3, and 48.0 respectively. Even though the pattern was similar in that varying

degrees of dysfunctioning was observed both the families of sicklers and diabetics reported moderately lower Total Impact scores than the normative group.

Section Three

Analysis of Differences of Mean Scores on Parenting Stress Index (PSI)

On the PSI, the scales chosen for analysis were the Depression, Social Isolation, and Relationship with Spouse. The scales were chosen for analysis because of their revelancy to the original research question. Table 4-7 outlines the mean raw scores for these PSI variables for the families of sicklers, diabetics, and nonillness controls.

Table 4-7
Mean Raw Scores of PSI Variables

Scale	Sicklers	Diabetics	Normals
Depression	18.9	21.9	22.7
S.D.	4.33	4.73	6.17
Social Isolation	12.5	16.0	14.4
S.D.	3.92	4.29	3.98
Relationship with Spouse	15.9	18.6	21.3
S.D.	4.09	4.41	5.12

On the PSI, all three groups were used in the analysis. Analysis of the depression scale was performed initially. The following hypothesis was formulated: There will be no significant differences between illness groups and nonillness controls on depression as measured by the PSI. The analysis revealed no significant effects were observed between families of sicklers, diabetics, and the nonillness controls. Table 4-8 shows this statistical relationship between the groups.

Table 4-8
Summary Table of MANOVA of PSI Variables

Scale	F-Value	Significance of F
Depression	2.229	.120
Social Isolation	3.236	.050
Relationship with Spouse	5.240	.009

Given that the MANOVA on the factor of depression did not exceed the critical value required for significance, the null hypothesis was accepted.

The Social Isolation variable was examined next. The following hypothesis was formulated: There will be no significant differences between illness groups and nonillness controls on social isolation as measured by the PSI. On the Social Isolation scale, the following results were obtained. MANOVA revealed significant effects between the three groups; $F(2,44) = 3.236$ $p<.05$. This statistical relationship is shown in Table 4-8. Further analysis using the t-test of independent means revealed that the significant relationship occurred between the families of sicklers and the families of diabetics, t (28) = 2.052 $p<.05$, and between families of sicklers and families of nonillness controls; t (28)= 2.048 $p<.05$. There were no significant differences found between families of diabetics and families of normal children. Sicklers reported lower scores on social isolation than both diabetics and nonillness controls. Since the MANOVA on the variable of Social Isolation exceeded the critical value required for significance the null hypothesis was rejected.

The final scale to be analyzed on the PSI was the Relationship with spouse. The following hypothesis was formulated: There will be

no significant differences between illness groups and nonillness controls on the Relationship with Spouse scale as measured by the PSI. On the Relationship with Spouse scale, MANOVA indicated significant effects were found between the groups, $F\ (2,44) = 5.240$ $p<.009$ as revealed in Table 4-8. T-test of independent means revealed that the significant effects were found between sicklers and normal controls, $t\ (28) = 2.048$ $p<.05$. No significant effects were found between sickler families and diabetic families, nor diabetic families and normal families. In this analysis, the normal families reported higher stress scores on this variable than both sickler and diabetic families. Since MANOVA on the factor of Relationship with Spouse exceeded the critical value required for significance the null hypothesis was rejected.

Section Four

Analysis of Differences of Mean Scores of Marital Satisfaction

In order to determine marital relationship patterns, the Locke-Wallace Marital Inventory was analyzed. The following hypothesis was formulated: There will be no significant differences on marital satisfaction between illness families and nonillness control families as measured by the Locke-Wallace Marital Inventory. Table 4-9 summarizes mean scores on the Locke-Wallace along with the statistical relationship between the groups.

ANOVA revealed no significant differences were observed between the groups. Since the ANOVA on the factor of marital satisfaction did not exceed the critical value required for significance, the null hypothesis was accepted.

Table 4-9
Mean Scores on Locke-Wallace Marital Inventory and Summary of ANOVA

Group	Mean	F-Value	Significance of F
sickler	93.5	.236	.791
S.D.	20.2		
diabetic	91.2		
S.D.	23.2		
Normal	88.0		
S.D.	21.3		

Section Five

Analysis of Differences of Mean Scores on IPAT Depression

The final variable to be addressed was depression of primary caretaker as measured by the IPAT. The following hypothesis was formulated: There will be no significant differences between illness groups and nonillness controls on depression as measured by the IPAT. The results of the ANOVA revealed no significant differences between the groups. These results are summarized in Table 4-10. The depression scores for all groups fell within normal range.

Table 4-10
Mean Scores on IPAT Depression Scale and Summary ofANOVA

Group	Mean	F-Value	Significance of F
sickler	6.0	2.503	.094
S.D.	1.92		
diabetic	7.5		
S.D.	1.80		
normal	6.5		
S.D.	2.03		

Since ANOVA on the factor of depression failed to exceed the critical value of significance, the null hypothesis was accepted.

Section Six

Analysis of Single Parent Data

Since information obtained in this section was not considered primary, no hypotheses were formulated. Analysis of data for single parents included selected variables of the PSI and the IPAT Depression Inventory. Table 4-11 summarizes the mean scores for single parent sicklers and controls on the PSI variables of Depression, Social Isolation, and Relationship with Spouse.

Table 4-11
Mean Raw Scores for Single Parents on PSI Variables

Scale	Sickler	Control
Depression	20.9	22.8
S.D.	6.29	4.78
Social Isolation	14.4	14.6
S.D.	5.33	4.55
Relationship with Spouse	21.9	19.8
S. D.	6.22	6.25

A MANOVA of the Depression factor revealed no significant differences between the two groups. On the variable of Social Isolation, again no significant differences were observed between the groups. Finally, on the variable of Relationship with Spouse/Child's Natural Father, no significance differences were observed. It should be noted that with single families on the PSI quesionnaire, instead of using the wording spouse, the phrase, child's natural father was inserted.

This phrasing was acceptable on the PSI. Table 4-12 summarizes the results of the MANOVA.

Table 4-12
Summary of MANOVA for Single Parents on PSI Variables

Scale	F-Value	Significance of F
Depression	5.77	.457
Social Isolation	.008	.929
Relationship With Child's Father	.566	.461

On the depression factor as measured by the IPAT, ANOVA revealed no significanct differences between the groups. Table 4-14 displays the results.

Table 4-13
Mean Scores on IPAT and Summary of ANOVA for Single Parents

Group	Mean	F-Value	Significance of F
sickler	7.6	1.236	.276
S.D.	1.71		
normal	6.3		
S.D.	1.49		

Section Seven

Some Additional Findings from the PSI

Included in this section is information from additional PSI scales, analysis of PSI Domain scores and a comparison of PSI percentile ranks for all families with the standardization group. Two other subscales on the PSI obtained significance between intact families, namely the

Parental Attachment and Sense of Competence, $F(2,44) = 4.100$ $p<.02$ and $F(2,44) = 3.236$ $p<.05$, "respectively." In terms of attachment, t-test of independent means revealed significant differences between families of sicklers and diabetics, $t(28) = 2.400$ $p<.05$, with sicklers reporting the significantly higher scores. Also significant effects were noted between nonillness controls and diabetics, $t(28) = 2.521$ $p<.05$, with the nonillness controls reporting the significantly higher scores. There were no significant differences between nonillness controls and sicklers. For both sickler families and normals their high scores suggest that there are possible two sources of dysfunctioning: (a) the parent does not feel a sense of emotional closeness to the child and/or (b) the parent's real or perceived inability to accurately read and understand the child's feelings.

T-test of independent means on the variable of Sense of Competence revealed significant effects of the variable between the nonillness control group and the sicklers with controls reporting the significantly higher scores, $t(38) = 2.363$, $p<.05$. These results suggested that the nonillness control parents are perceiving themselves as lacking in practical child development knowledge and possessing a limited range of child management skills. Also, high scores may be found among parents who do not find the role of parenting reinforcing as they had expected. There were no significant differences between diabetic families and controls as well as between diabetic and sickler families. However, diabetics obtained very similar mean scores as the nonillness controls as shown by the small variation in the mean scores 33.9 and 34.1 "respectively."

For single parents, significant differences were observed on the variables of Child Reinforces Parent, $F(1,18) = 4.417$ $p<.03$, and Parental Attachment, $F(1,18) = 5.455$ $p<.03$. On both the Attachment scale and Child Reinforces Parent the nonillness control group reported significantly higher dysfunctioning scores than the sicklers. A description of these scales can be found in the Method section.

Analysis of PSI Domain Scores

PSI Domain scores for intact family groups were compared to the standardization sample. Interesting results were observed. An analysis of Domain scores between groups are summarized in Table 4-14. No significant differences were observed between mean scores of the three groups.

Table 4-14
Summary Table of MANOVA PSI Domain Scores

Scale	F-Value	Significance of F
Total Domain Score	1.821	.175
Child Domain Score	.843	.438
Parent Domain Score	2.966	.063

When compared to the normative group, the mean score of 124 obtained by the nonillness control group on the child characteristic domain is considered a high score on this measure. Similarly, the nonillness control group obtained a Total Domain score of 269 which is also considered a high score on this measure. These results seemed to signify that overall even though there were no significant differences between the groups, the nonillness control family system

was reporting greater stress than the illness groups in these two domains. Domain scores for single parents were examined next. The statistical relationship between the Domain scores for single parents are summarized in Table 4-15.

Table 4-15
Summary of MANOVA for Single Parent Domain Scores

Scale	F-Value	Significance of F
Total Domain Score	.869	.363
Child Domain Score	.452	.510
Parent Domain Score	1.189	.290

The analysis failed to reveal any significant differences. Noteworthy, however, is the nonillness control group's Total Domain score of 261 which fell within the high score range. Again, the suggestion is that this parent-child system is more under stress and at risk compared to the illness group.

Finally, a comparison of percentile ranks proved interesting. Table 4-16 displays percentile ranks for a normal family on the PSI. The normal range of percentile scores as described in the manual fall between the 15th and 80th percentile. Table 4-17 displays percentile ranks for the intact sickler family. The range of scores fell between 35th and 90th percentile with five out of seven variables in the child domain lying outside of the normal range. Only one out of seven in the parent domain fell outside the normal range. Table 4-18 displays percentile ranks for intact diabetic families. The range of scores lies between the 45th and 90th percentile. Here four

Table 4-16
Parenting Stress Index Profile Sheet and Norms
Normative Sample

	Raw Score	1	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	99	x	SO
TOTAL STRESS SCORE	205	31	157	170	179	188	195	201	208	214	217	221	224	228	223	239	244	250	258	267	293	320	221.1	38.9
CHILD SCORE	94	30	66	73	78	82	87	89	92	95	97	99	100	102	105	107	110	114	116	122	130	145	98.4	19.2
Adaptability	28	7	15	17	19	20	21		22	23		24	25		26	27		28	30	31	33	138	24.5	5.7
Acceptability	10	4	6	7	8	9		10		11		12		13		14		15	16	17	18	21	12.5	3.6
Demandingness	19	8	10	12	13	14	15		16		17		18		19	20	21		22	24	25	31	18.1	4.6
Mood	7	3	5		6		7		8		9		10				11		12	13	14	18	9.6	2.9
Distric./Hyper.	22	12	16	18	19	20	21		22		23		24	25	26		27	28	29	31	33	36	24.4	5.0
Reinforces Parent	8	5			6				7		8		9		10			11		12	15	18	9.3	2.9
PARENT SCORE	111	69	82	90	99	102	107	110	112	115	118	121	123	126	129	132	137	141	148	153	168	188	122.7	24.6
Depression	20	8	12	13	15	16		17	18		19	20		21		22	23	24	26	27	30	36	20.4	5.6
Attachment	9	6	7	8	9		10		11		12			13		14			15	16	17	22	12.6	3.1
Restric. of Role	21	8	11	12	13	14	15	16		17	18		19		20	21	22	23	24	26	29	32	19.0	5.2
Competence	23	15	18	21	22	23	24	25	26	27	28		29	30	31	32	33	34	35	37	40	45	29.2	6.3
Social Isolation	11	6	7	8	9		10		11		12		13		14	15	16		17	18	20	22	12.8	3.8
Relat. with Spouse	16	6	8	10	11	12	13		14	15	16	17		18	19	20	21		22	23	26	28	16.8	5.1
Parent Health	11	5	7	8		9			10		11			12		13	14		15	16	18	21	11.9	3.3

Source: Abidin, 1983

Table 4-17
Parenting Stress Index Profile Sheet and Norms
Sickler Families

	Raw Score	1	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	99	x	SD
TOTAL STRESS SCORE	242	31	157	170	179	188	195	201	208	214	217	221	224	228	223	239	244	250	258	267	293	320	221.1	38.9
CHILD SCORE	117	50	66	73	78	82	87	89	92	95	97	99	100	102	105	107	110	114	116	122	130	145	98.4	19.2
Adaptability	27	7	15	17	19	20	21		22	23		24	25		26	27		28	30	31	33	138	24.5	5.7
Acceptability	16	4	6	7	8	9		10		11		12		13		14		15	16	17	18	21	12.5	3.6
Demandingness	22	8	10	12	13	14	15		16		17		18		19	20	21		22	24	25	31	18.1	4.6
Mood	12	3	5		6		7		8			9		10			11		12	13	14	18	9.6	2.9
Distric./Hyper.	25	12	16	18	19	20	21		22		23		24	25	26		27	28	29	31	33	36	24.4	5.0
Reinforces Parent	13	5			6				7		8		9		10			11	12	15	18	9.3	2.9	
PARENT SCORE	125	69	82	90	99	102	107	110	112	115	118	121	123	126	129	132	137	141	148	153	168	188	122.7	24.6
Depression	18	8	12	13	15	16		17	18		19	20		21		22	23	24	26	27	30	36	20.4	5.6
Attachment	15	6	7	8	9		10		11		12			13		14			15	16	17	22	12.6	3.1
Restric. of Role	18	8	11	12	13	14	15	16		17	18		19		20	21	22	23	24	26	29	32	19.0	5.2
Competence	28	15	18	21	22	23	24	25	26	27	28		29	30	31	32	33	34	35	37	40	45	29.2	6.3
Social Isolation	12	6	7	8	9		10		11			12		13		14	15	16	17	18	20	22	12.8	3.8
Relat. with Spouse	15	6	8	10	11	12	13		14	15		16	17		18	19	20	21	22	23	26	28	16.8	5.1
Parent Health	13	5	7	8		9			10			11			12		13	14	15	16	18	21	11.9	3.3

Source: Abidin, 1983

Table 4-18
Parenting Stress Index Profile Sheet and Norms
Diabetic Families

	Raw Score	1	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	99	x	SD
TOTAL STRESS SCORE	251	31	157	170	179	188	195	201	208	214	217	221	224	228	223	239	244	250	258	267	293	320	221.1	38.9
CHILD SCORE	115	50	66	73	78	82	87	89	92	95	97	99	100	102	105	107	110	114	116	122	130	145	98.4	19.2
Adaptability	27	7	15	17	19	20	21		22	23		24	25		26	27		28	30	31	33	138	24.5	5.7
Acceptability	15	4	6	7	8	9		10		11		12		13		14		15	16	17	18	21	12.5	3.6
Demandingness	24	8	10	12	13	14	15		16		17		18		19	20	21		22	24	25	31	18.1	4.6
Mood	12	3	5		6		7		8			9		10			11		12	13	14	18	9.6	2.9
Distric./Hyper.	23	12	16	18	19	20	21		22		23		24	25	26		27	28	29	31	33	36	24.4	5.0
Reinforces Parent	12	5			6				7		8		9		10			11	12	15	18	9.3	2.9	
PARENT SCORE	136	69	82	90	99	102	107	110	112	115	118	121	123	126	129	132	137	141	148	153	168	188	122.7	24.6
Depression	21	8	12	13	15	16		17	18		19	20		21		22	23	24	26	27	30	36	20.4	5.6
Attachment	14	6	7	8	9		10		11			12			13		14		15	16	17	22	12.6	3.1
Restric. of Role	20	8	11	12	13	14	15	16		17	18		19		20	21	22	23	24	26	29	32	19.0	5.2
Competence	33	15	18	21	22	23	24	25	26	27	28		29	30	31	32	33	34	35	37	40	45	29.2	6.3
Social Isolation	16	6	7	8	9		10		11			12		13		14	15	16	17	18	20	22	12.8	3.6
Relat. with Spouse	18	6	8	10	11	12	13		14	15		16	17		18	19	20	21	22	23	26	28	16.8	5.1
Parent Health	11	5	7	8		9			10			11			12		13	14	15	16	18	21	11.9	3.3

Source: Abidin, 1983

Table 4-19
Parenting Stress Index Profile Sheet and Norms
Nonillness Control Families

	Raw Score	1	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	99	x	SD
TOTAL STRESS SCORE	269	31	157	170	179	188	195	201	208	214	217	221	224	228	223	239	244	250	258	267	293	320	221.1	38.9
CHILD SCORE	124	50	66	73	78	82	87	89	92	95	97	99	100	102	105	107	110	114	116	122	130	145	98.4	19.2
Adaptability	29	7	15	17	19	20	21		22	23		24	25		26	27		28	30	31	33	138	24.5	5.7
Acceptability	17	4	6	7	8	9		10		11		12		13		14		15	16	17	18	21	12.5	3.6
Demandingness	23	8	10	12	13	14	15		16		17		18		19	20	21		22	24	25	31	18.1	4.6
Mood	12	3	5		6		7		8			9		10			11		12	13	14	18	9.6	2.9
Distric./Hyper.	27	12	16	18	19	20	21		22		23		24	25	26		27	28	29	31	33	36	24.4	5.0
Reinforces Parent	14	5			6				7		8		9		10			11		12	15	18	9.3	2.9
PARENT SCORE	145	69	82	90	99	102	107	110	112	115	118	121	123	126	129	132	137	141	148	153	168	188	122.7	24.6
Depression	22	8	12	13	15	16		17	18		19	20		21		22	23	24	26	27	30	36	20.4	5.6
Attachment	17	6	7	8	9		10		11			12			13		14		15	16	17	22	12.6	3.1
Restric. of Role.	22	8	11	12	13	14	15	16		17	18		19		20	21	22	23	24	26	29	32	19.0	5.2
Competence	34	15	18	21	22	23	24	25	26	27	28		29	30	31	32	33	34	35	37	40	45	29.2	6.3
Social Isolation	15	6	7	8	9		10		11			12		13		14	15	16	17	18	20	22	12.8	3.8
Relat. with Spouse	21	6	8	10	11	12	13		14	15		16	17		18	19	20	21	22	23	26	28	16.8	5.1
Parent Health	12	5	7	8		9			10			11			12		13	14	15	16	18	21	11.9	3.3

Source: Abidin, 1983

Table 4-20
Parenting Stress Index Profile Sheet and Norms
Sickler Single Parent Families

	Raw Score	1	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	99	x	SD
TOTAL STRESS SCORE	241	31	157	170	179	188	195	201	208	214	217	221	224	228	223	239	244	250	258	267	293	320	221.1	38.9
CHILD SCORE	112	50	66	73	78	82	87	89	92	95	97	99	100	102	105	107	110	114	116	122	130	145	98.4	19.2
Adaptability	28	7	15	17	19	20	21		22	23		24	25		26	27		28	30	31	33	138	24.5	5.7
Acceptability	15	4	6	7	8	9		10		11		12		13		14		15	16	17	18	21	12.5	3.6
Demandingness	22	8	10	12	13	14	15		16		17		18		19	20	21		22	24	25	31	18.1	4.6
Mood	10	3	5		6		7		8			9		10			11		12	13	14	18	9.6	2.9
Oistric./Hyper.	25	12	16	18	19	20	21		22		23		24	25	26		27	28	29	31	33	36	24.4	5.0
Reinforces Parent	11	5			6				7		8		9		10			11		12	15	18	9.3	2.9
PARENT SCORE	128	69	82	90	99	102	107	110	112	115	118	121	123	126	129	132	137	141	148	153	168	188	122.7	24.6
Depression	20	8	12	13	15	16		17	18		19	20		21		22	23	24	26	27	30	36	20.4	5.6
Attachment	13	6	7	8	9		10		11			12			13		14		15	16	17	22	12.6	3.1
Restric. of Role	18	8	11	12	13	14	15	16		17	18		19		20	21	22	23	24	26	29	32	19.0	5.2
Competence	31	15	18	21	22	23	24	25	26	27	28		29	30	31	32	33	34	35	37	40	45	29.2	6.3
Social Isolation	14	6	7	8	9		10		11			12		13		14	15	16	17	18	20	22	12.8	3.8
Relat. with Spouse	21	6	8	10	11	12	13		14	15		16	17		18	19	20	21	22	23	26	28	16.8	5.1
Parent Health	13	5	7	8		9			10			11			12		13	14	15	16	18	21	11.9	3.3

Source: Abidin, 1983

Table 4-21
Parenting Stress Index Profile Sheet and Norms
Single Parent Nonillness Control Families

	Raw Score	1	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	99	x	SD
TOTAL STRESS SCORE	261	31	157	170	179	188	195	201	208	214	217	221	224	228	223	239	244	250	[258]	267	293	320	221.1	38.9
CHILD SCORE	120	50	66	73	78	82	87	89	92	95	97	99	100	102	105	107	110	114	116	[122]	130	145	98.4	19.2
Adaptability	27	7	15	17	19	20	21		22	23		24	25		26	[27]		28	30	31	33	138	24.5	5.7
Acceptability	16	4	6	7	8	9		10		11		12		13		14		15	[16]	17	18	21	12.5	3.6
Demandingness	21	8	10	12	13	14	15		16		17		18		19	20	[21]		22	24	25	31	18.1	4.6
Mood	12	3	5		6		7		8			9		10			11		[12]	13	14	18	9.6	2.9
Distric./Hyper.	27	12	16	18	19	20	21		22		23		24	25	26		[27]	28	29	31	33	36	24.4	5.0
Reinforces Parent	15	5			6				7		8		9		10			11		12	[15]	18	9.3	2.9
PARENT SCORE	141	69	82	90	99	102	107	110	112	115	118	121	123	126	129	132	137	[141]	148	153	168	188	122.7	24.6
Depression	22	8	12	13	15	16		17	18		19	20		21		[22]	23	24	26	27	30	36	20.4	5.6
Attachment	16	6	7	8	9		10		11			12			13		14		15	[16]	17	22	12.6	3.1
Restric. of Role	21	8	11	12	13	14	15	16		17	18		19		20	[21]	22	23	24	26	29	32	19.0	5.2
Competence	33	15	18	21	22	23	24	25	26	27	28		29	30	31	32	[33]	34	35	37	40	45	29.2	6.3
Social Isolation	14	6	7	8	9		10		11			12		13		[14]	15	16	17	18	20	22	12.8	3.8
Relat. with Spouse	19	6	8	10	11	12	13		14	15		16	17		18	[19]	20	21	22	23	26	28	16.8	5.1
Parent Health	12	5	7	8		9			10			11			[12]		13	14	15	16	18	21	11.9	3.3

Source: Abidin, 1983

out of five of the child domain scoress fell outside of the normal range. Table 4-19 displays percentile scores for intact normal control families. The range of scores fell between the 65th and 95th percentile. Total Stress score, along with six out of seven Child Domain scores fell outside of the normal range. This was the only group whose Parent Domain score fell outside of the normal range. Table 4-20 displays percentile ranks of single parent sickler families. The range of scores were between the 45th and 85th percentile. Only one scale fell outside of the normal range. Lastly, Table 4-21 displays the percentile ranks for the single parent normal families. The range of scores fell between the 65th and 95th percentile. The Total Stress score and four of the seven variables in the child domain fell outside of the normal rnage of percentile ranks.

Summary of percentile ranks reveals that diabetic and sickler families are similar overall, although there may be some individual variables which cause them to differ. The data indicated that all the families appeared to be experiencing varying amounts of stress, mostly related to child characteristics rather than the parenting subsystem. An interesting finding was that in both the intact and single parent nonillness families a similar pattern emerged, that is the appearance of a greater dysfunctioning pattern within the family unit compared to the illness families.

CHAPTER 5
SUMMARY, DISCUSSION, RECOMMENDATIONS AND CONCLUSIONS

Summary

This research project was designed to examine the extent to which sickle cell disease impacted on family functioning. Selected variables were chosen for study. Sickle cell disease families were compared to both an illness control group as well as a nonillness group. The design was intended to yield information on the psychosocial impact of a chronic illness on family dynamics and relationships.

The subjects for the study were 15 sickle cell families, 15 diabetic families, and 15 nonillness control families recruited from across southeast Georgia and north Florida. The sample consisted of families demographically who ranged from mean incomes of 18,000 to 27,000 dollars a year, mean age of identified child of 6.4 to 6.7 years, mean family size of 4.7 children and 80 percent of mothers and fathers high school graduates and above. The only exception was found with sickler mothers where only 70 percent of them were high school graduates.

Data were collected for all subjects on the variables of Social Isolation, Depression and Relationship with Spouse by use of the Parenting Stress Index. An additional measure of depression was collected on the IPAT Depression Inventory. Data were collected for all families on the Locke-Wallace Marital Inventory, a measure of

marital satisfaction. Data were collected for sickler and diabetic families on the variables of Financial Impact, Disruption of Social Relationships, and Total Impact of Illness by use of the Impact of Illness on Family Scale.

The data were analyzed by use of both single classification analysis of variance (ANOVA) and by the use of multivariate classification analysis of variance (MANOVA) to determine whether significant differences occurred between the means, requiring F-ratios significant at or beyond the .05 level of significance. Where significant F ratios were found, the t-test of independent means was used to determine where the significance existed internally.

The findings of the study are summarized as follows:

1. There were no significant differences between sickler and diabetic families on how the illness affected their financial resources. Both groups obtained scores in the range similar to the normative group which when interpreted suggested that the illness had an adverse impact on the family's economic resources. This impact was characterized by additional income needed and increased medical expenses in families with chronic illness. This finding was expected and consistent with previous literature.

2. There were significant differences between sickler and diabetic families on how the illness impacted on their social relationships as measured by the IFS. In this comparison, diabetics reported that the illness adversely affected their social patterns more so than sicklers. This impact was characterized by the family spending less time with friends, parents having little desire to socialize, and plans often having to be changed. Even though there was a significant effect noted

between the illness groups, when compared to the normative sample, similar means were observed for all groups. Again, the indication is that both families are affected socially, with diabetics perceiving the greater effect.

3. There were no significant differences between sickler and diabetic families on the way the total impact of illness was perceived. When compared to the normative sample a similar range of scores emerged. Impact scores of the magnitude obtained by the two groups are associated with the mother's perception that her child is difficult to care for, increased number of hospitalizations, mother's report that the illness has affected her life, lack of social support, and increased psychiatric symptoms on the part of the mother.

4. There were no significant differences between sicklers, diabetics, and nonillness families on the depression measure as measured by the PSI. All groups obtained scores that fell within the normal range. These results suggested that for the most part there was no indication of significant depression in the mother as primary caretaker. The parent did not find it difficult to mobilize psychic and physical energy to fulfill parenting responsibilities. There seemed to be little dissastifaction with self and/or life circumstances.

5. There were significant differences between sicklers, diabetics, and nonillness families on the social isolation variable as measured by the PSI. Both diabetics and nonillness families reported higher scores than did sickler families. These parents reported they were socially isolated from their peers, relatives, and other emotional support systems. These findings were not as expected in that it was thought

that diabetic and sickler families would report greater amounts of social isolation than normal controls. Instead, greater isolation was reported by diabetic families and normal controls.

6. There were significant differences between sickler, diabetic, and nonillness families on the relationship with spouse variable as measured by the PSI. As seen with the previous scale, diabetics and nonillness controls reported significantly higher scores on this variable. These results suggested that both diabetics and controls are perceiving a lack of emotional and active support of the other parent in the area of child management. The relationship between mother and father does not appear to be positive and there is a lack of mutual support in the child care arena. Again, these results were somewhat unexpected in that it was anticipated that the illness groups would obtain the higher scores versus the nonillness group reflecting the impact of the illness on the spousal relationship.

7. There were no significant differences between sickler, diabetic and nonillness families on marital satisfaction as measured by the Locke-Wallace. However, an interesting comparison emerged between mean scores of the present sample and the standardization one. Mean scores of the present sample were 93.5, 91.2, and 88.0. The mean adjustment score for the well-adjusted normative group was 135.9, whereas the mean score for the maladjusted group was 71.9. At first glance, it may seem that all three groups in the present sample were somewhat maladjusted in their marital relationships. However, it is more likely that due to demographic dissimilarity of the present sample and the normative group, the results reflect an incompatibility of the instrument to the population assessed.

8. There were no significant differences between sicklers, diabetics, and nonillness controls on depression as measured by the IPAT. Primary caretakers reported very little depression across all three groups. This finding is inconsistent with what has been reported in the literature, but consistent with other instrumentation used in this study.

Discussion

The results of this investigation were somewhat surprising. What was expected was not always supported. The study expected no differences to emerge between illness groups (diabetics and sicklers) and that an impact of illness would be observed on the hypothesized variables which would be manifested by the illness groups having greater dysfunctioning scores on the measures. This pattern seemed to hold true for diabetics, but not for the sicklers. What was even more intriguing was that the non-illness control group obtained higher dysfunctioning scores on two of the selected variables than both sicklers and diabetics. Could it have been that the normal families were just more dysfunctional than the illness families, or, were there attributional differences in that families of sick children attributed stressors to the illness, whereas normal families attributed faults to members of the family system? In the Rationale section of this paper, the investigator proposed the question of whether sickle cell disease families were impacted differently by the disease than has been shown for other chronic illness groups. Is the answer "yes" or, are there other explanations that can be offered? The investigator proposed some explanations below.

Coping Strategies. It is suspected that the family of a chronically ill child is faced with two choices: (1) they either succumb to the debilitating effects of the disease and risk destruction of the family

or (2) they develop a coping mechanism by which they learn to modulate the negative effects such that they can maintain a semblance of family stability. It is almost akin to the idiom "adversity leads to solution, resolution or dissolution." Evidence of this was noted not from the questionnaire data provided in the study, but when the investigator encouraged open discussion. Parents of SCD children spoke about a higher power, i.e. God, and the belief that there was a reason for their children being ill and the resulting adversities that followed. However, their faith in this power gave them the strength and endurance to master whatever problems that developed.

Denial. Another explanation that can be offered was also gleamed from talking with parents in open discussion; that is parents may deny they are having problems. They deny difficulties because admitting problems to others might suggest they are incapable of dealing with the illness, which may ultimately lead to feelings of guilt. Sickler parents appeared somewhat more suspicious and wanted to know more frequently what the information was going to be used for. They were also more likely to change an answer from a more problematic one to what appeared to be a less problematic one. Grier and Cobb (1969) theorized that within the black culture, there is a built-in paranoia that developed from a history of subjugation and cruelty. According to these authors, this paranoia serves as an adaptive healthy defense mechanism. Through its functioning, it allows some members of the black culture to rationalize being "on guard" especially when confronted with real of symbolic elements that represent the dominant society. Black individuals learn how not to admit frailities for fear of it being used against them, as has been the

case many times in the past. This may account for the failure to observe an "illness impact" on the sickle cell intact and single parent families as had been observed among the diabetic families.

Incompatibility of Instrumentation. A third explanation, which follows a similar theme as the one above, questions whether the concepts that were hypothesized to differentiate groups were adequately measured and assessed. In family research literature, there are a multitude of constructs that are utilized, but very few have been scrutinized and concretized in terms of operationalizing them for measurement purposes. The question becomes are we asking the appropriate questions and even more importantly are the instruments used adequately fitting the bill to measure what we are trying to find out? It is the author's contention that the instrumentation used in this study did not adequately address the issues and dynamics of the black chronically ill family experience because of their standardization procedures and questionable validity of items chosen for study. The instrumentation was more useful in assessing difficulties for the diabetic families because they were similar demographically to the standardization groups. The more similar a group is to the sample that was used to standardized the instrument, the more likely the results will be valid and reliable.

Expectations. Parents of normal children more than like have different expectations of their children than parents of ill children. A chronic illness narrows the range of experiences that a child will and can be exposed to. Given that there are less possible experiences, there are less possible stressors. In addition, it is often the case that black parents are less financially able to expose their children or themselves to as many experiences as they would like to. Lack of

exposure to something not only can keep one from benefitting from the advantages, but may also shield one from the possible disadvantages.

In the present study even though incomes of diabetic families were not significantly different from the other groups, their incomes were greater. This suggested they had more in terms of financial resources and probably more able to afford the things they enjoyed. The illness more than likely affected the physical aspects of being able to participate in the activities they enjoyed thereby causing more stress in the system. The expectation is that the more money one has to his or her disposal the more fulfilling one's life can be. However, because of the presence of a chronic illness this may not have always been the case.

For parents who have normal children they may have more dreams, hopes, and expectations for their children as well as themselves. They strive at a different level to achieve the goals that they have set. As a result there is potentially greater stress that permeates various aspects of family functioning, i.e. marital, social. This may hold more true for normal families than illness families because the goals and expectations have to be viewed from the standpoint of coexisting with a chronic illness.

Recommendations and Conclusions

Further research is recommended in the following areas: epidemiology, methodology, and assessment. An epidemiological study is in order to learn more about sickle cell families in terms of their demographical make-up. Once more is known about the structural aspects of these families, more appropriate and intelligent design questions can be formulated. In terms of methodology, it appears the most appropriate design is one

where a longitudinal study is utilized. Parents talked in the open discussion about different "stress periods" such as right after diagnosis and during crises episodes. A longitudinal study would allow for an assessment of critical periods and identify possible causation factors. In the assessment area we need more normative data on black families. How can one begin to talk about dysfunctioning within the black family without having at least some knowledge about how normal black families function? When instruments are used that are standardized primarily on white middle class Anglo-Saxons, we run the risk of being unable to generalize to the populations that are different. When this is the case we must then question whether our results are valid and reliable.

In this study there were several other methodological weaknesses. The small sample size could have possibly minimized or exaggerated differences between the groups. There were possibly inappropriate assessment techniques used. In terms of illness variables, the author's failure to adequatly control for severity and duration of illness could have biased the result in some particular direction. Finally, whether a diabetic control group was an appropriate one is questionable in that diabetes tend to have a different clinical course than SCD. Diabetes seems to have a pervasive impact, whereas it is often only during "crises" periods that the effects of SCD are more pronounced and remembered.

In light of the findings of the study a major implication is the need for more research. Studies would need to employ more appropriate control groups as well as utilizing instrumentation that has been standardized and validated on similar populations to the ones being

studied. The findings tend to support that the impact of SCD on family functioning is mostly in the economic arena. The impact in other areas hypothesized was not as clearly delineated as what has been theorized or shown empirically by other researchers examining other chronic illnesses. This study did little in the way of identifying specific areas, but did raise interesting questions as to whether the variables that have been traditionally observed to be impacted by a chronic illness are the same ones that are of importance for SCD families.

APPENDIX

CONSENT TO PARTICIPATE IN A STUDY EXAMINING THE PSYCHOLOGICAL EFFECTS OF SICKLE CELL DISEASE ON FAMILY FUNCTIONING

1. You are being asked to participate in a research study involving the effects of sickle cell disease on family functioning. The purpose of this study is to determine the ways in which having a child with sickle cell disease affects a family's social and psychological well-being. The study is being conducted by Ms. Cynthia Cone-Dekle, a student at the University of Florida. She may be contacted by telephone at _____. It is hoped that the information obtained from this study will lead to a better understanding of how families are affected by chronic illness, and in particular by sickle cell disease, so that the special needs of these families can be met more effectively.

2. This study will involve three different groups of families: 1) families with a child suffering from sickle cell disease; 2) families with a child suffering from juvenile diabetes; and 3) families in which all of the children are healthy. The information obtained from the families of children with juvenile diabetes and the families of healthy children will be compared with the information obtained from the families of children with sickle cell disease to determine the ways in which these families compare and differ.

3. Your participation in this study will consist of one interview with the researcher during which you will be asked questions about yourself and your family. You will be asked to complete several questionnaires.

4. There may be no direct benefit to you from participating in this study. However, your participation in this study may eventually benefit the families of children with chronic illnesses, particularly those families of children with sickle cell disease, by providing information about the special needs and problems of these families.

5. The records maintained in connection with this study will be confidential except that they may be used in compiling statistical data and other data in connection with the publication of the description of the study and its results.

6. You will not receive any compensation for participating in this study. If any injury occurs to you as the result of your participation in the study neither _____Hospital nor the researchers involved in the study will make any compensation for such injury. However, the researcher involved in the study will aid you in making appropriate arrangements for treatment of any such injuries. Further information may be obtained from Ms. Cynthia Cone-Dekle.

7. Participation in this study is voluntary and if you refuse to participate you will not be penalized or lose any benefits to which you would otherwise be entitled. You may also discontinue your participation in this study at any time without being penalized or lose any benefits to which you would otherwise be entitled.

I hereby consent to participate in the research study described above. I have read and understood the information contained in this consent form and I have asked any questions I have of the researcher involved in this study.

_____
Witness

_____
Signature of Study Participant

_____
Date

REFERENCES

Ackerman, N. Treating the troubled family. New York: Basic Books, 1966.

Abidin, R. Parenting Stress Index-Manual. Charlottesville, Virginia: Pediatric Psychology Press, 1983.

Awalt, S.J. Transistion to parenthood: Predictors of individual and marital stability and change (Doctoral dissertation, University of California-Berkley, 1981). Dissertation Abstracts International, 1983, 43, 2792A. (University Microfilms No. 83-00, 406).

Bowen, M. The use of family theory in clinical practice. In J. Haley (ed.) Changing families: A family therapy reader. New York: Grune and Stratton, 1971.

Breslau, N., Staruch, K., and Mortimer, E. Psychological distress in mothers of disabled children. American Journal of Disabled Children, 1982, 136, 682-686.

Bruner, J. Toward a therapy of instruction. Cambridge: Harvard University Press, 1966.

Burke, W.T. and Abidin, R. The development of a Parenting Stress Index. Paper presented at the meeting of the American Psychological Association, Washington, D.C., August 1978.

Burton, L. The family of sick children: A study of families coping with chronic childhood disease. London: Routledge and Kegan Paul Publisher, 1975.

Casey, B. Recurrent serous otitis media: Its impact on the cognitive performance and social adjustment of preschool children (Doctoral dissertation, University of Virginia, 1983). Dissertation Abstracts International, 43, 3355B.

Cerami, A. and Washington, E. Sickle cell anemia. New York: Joseph Okapu Publishing Company, 1974.

Charmaz, K. Time and identity: The shaping of selves of the chronically ill (Doctoral dissertation, University of California-San Francisco, 1973). Dissertation Abstracts International, 1973, 34, 3541A. (University Microfilms No. 73-29, 923).

Debuskey, M. editor. The chronically ill child and his family. Springfield, Illinois: C. Thomas Publisher, 1970.

Gayton, W., Friedman, S., Tavormina, J., and Tucker, R. Children with cystic fibrosis: Psychological test findings of parents and siblings. Pediatrics, 1982, 15, No. 1, 23.

Graham, A., Reeb, K., Levitt, C., Fine, M., and Medalie, J. Care of a troubled family and their child with sickle cell anemia. The Journal of Family Practice, 1982, 15, No.1, 23.

Greenberg, D. Support systems and parent stress in families with trainable mentally retarded youngsters (Doctoral dissertation, University of Pennsylvania, 1983). Dissertation Abstracts International, 1983, 44, 1029A. (University Microfilms No. 83-16, 026)

Grier, W.H. and Cobb, P.M. Blackrage. New York: Bantam Books, 1969.

Krug, S. and Laughlin, J. Handbook for the IPAT Depression Scale. Champaign, Illinois: Institute for Personality and Ability Testing, 1976.

Lafiosca, T. The relationship of parent stress to anxiety, approval, motivation, and children behavior problems (Doctoral dissertation, University of Virginia, 1983). Dissertation Abstracts International, 1983, 43, 3366B. (University Microfilms No. 82-28, 647)

Leavell, S. and Ford, C. Psychopathology in patients with sickle cell disease. Psychomatics 1983, 24, No.1, 23.

Lehman, H. and Cutbush, M. Sickle cell trait in Southern India. British Medical Journal, 1952, 1, 404.

Linde, S. Sickle cell: A complete guide to prevention and treatment. New York: Pavilion Publishing Company, 1972.

Lipowski, Z.J. Physical illness, the individual and coping process. Psychiatric Medicine, 1970, 1, 91.

Locke, H. and Wallace, K. Short marital adjustment and prediction tests; their reliability and validity. Marriage and Family Living, 1959, 10, 251.

Maurin, J. and Schenkel, J. A study of the family unit's response to hemodialysis. Journal of Psychosomatic Research, 1976, 10, 163.

McCollum, J.K. The chronically ill child. New Haven and London: Yale University Press, 1981.

McMichael, J.K. Handicap: A study of physically handicapped children and their families. London: Staples Press, 1971.

Neel, J.V. The inheritance of the sickling phenomenon, with particular reference to sickle cell disease. Blood, 1951, 6, 389.

Saviano, M.A. Maternal involvement in the implementation of occupational therapy with severely handicapped children and deficits in feeding. Unpublished masters thesis, Washington University, St. Louis, Missouri, 1981.

Shukla, R.N. and Solanki, B.R. Sickle cell trait in Central India. Lancet, 1958, 1, 297.

Stein, R.K. and Jessop, D. Tables documenting the psychosomatic properties of a measure of the Impact of Illness on Family Scale (Pediatric Ambulatory Care Treatment Study). Unpublished manuscript, Albert Einstein College, 1985.

Straus, A. and Glaser, B. Chronic illness and the quality of life. St. Louis: The C.V. Mosby Company, 1975.

Tew, B. and Laurence, K. Mothers, brothers and sisters of parents with spina bifida. Developmental Medicine in Child Neurology, 1973, 15 (Supplement 2a), 69.

Turk, J. Impact of cystic fibrosis on family functioning. Pediatrics, 1964, 34, 67.

Vassassuer, J. A comprehensive program for meeting psychological needs of sickle cell anemia patients. Journal of the National Medical Association, 1977, 69, No.5, 335.

Whitten, C. and Fischoff, J. Psychosocial effects of sickle cell disease. Archives of Internal Medicine, 1974, 133, 682.

Williams, I., Earles, A., and Pack, B. Psychological considerations in sickle cell disease. Nursing Clinics of North America, 1983, 18, No. 1, 215.

Zimmerman, J.L. The relationship between support systems and stress in families with a handicapped child. (Doctoral dissertation, University of Virginia, 1979). Dissertation Abstracts International, 1981, 41, 3597B. (University Microfilms No. 81-01, 065)

BIOGRAPHICAL SKETCH

Cynthia Cone-Dekle was born in Bulloch County, Georgia, in 1956 to Mr. and Mrs. Ed Foy Cone. She completed her eary education in the Bulloch County School System. Her formal education began in 1974 at Oglethorpe University in Atlanta, Georgia. There she majored in psychology and obtained a minor in sociology. While at Oglethorpe, she involved herself in several organizations both social and honorary. She graduated magna cum laude from Oglethorpe in 1978. She continued her formal training at the University of Florida at Gainesville. Her major speciality was the area of clinical psychology. She spent a years' internship with the Georgia Mental Health Institute with major emphasis in child psychology.

Ms. Dekle is married and the mother of two children. Her hobbies include sewing, reading, exotic cooking, and spending time engaging in activities which involve promoting social change. She also enjoys poetry writing and is a published poet.

Her membership affiliations include Who's Who Among American Colleges and Universities, Omicron Delta Kappa, the National Association for the Advancement of Colored People, and the Statewide Minority Advocacy Group for Alcohol and Drug Prevention.

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.

Eileen Fennell, Chair
Professor of Clinical and Health Psychology

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosohpy.

Hugh Davis
Professor of Clinical and Health Psychology

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James Johnson
Professor of Clinical and Health Psychology

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Mary McCaulley
Assistant Professor of Clinical and Health Psychology

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.

Rod McDavis
Professor of Counseling Psychology

This dissertation was submitted to the Graduate Faculty of the College of Health Related Professions and to the Graduate School and was accepted as partial fulfillment of the requirements for the degree of Doctor of Philosophy.

April 1988

Dean, College of Health Related Professions

Dean, Graduate School